



***Family Voices of Illinois***

***The Arc of Illinois***

***Family to Family Health Information Center***

[www.familyvoicesillinois.org](http://www.familyvoicesillinois.org)

[familytofamily@thearcofil.org](mailto:familytofamily@thearcofil.org)

708-560-6703 (voice) 866-931-1110 (toll free for Illinois families)

**November 19, 2013**

**To: Health and Medicine Policy Research Group**

**Re: Family Voices of Illinois Comments on 1115 Waiver Concept Paper**

Thank you for affording us this opportunity to share our comments regarding the Illinois Department of Health Care and Family Services 1115 Waiver Concept Paper.

Family Voices of Illinois represents families and professionals caring for children up to age 21 with special health care needs, disabilities and/or chronic illnesses. We are part of a national network of Family to Family Health Information Centers funded by the Health Services and Resources Administration (HRSA) Maternal and Child Health Bureau (MCHB).

In light of the fact that all of us are awaiting additional information regarding Illinois' proposed 1115 waiver, we are sharing recommendations based upon our experiences at our Family to Family Health Information Center (F2FHIC) over the past eight years.

## **1. Home and Community Based Infrastructure, Coordination and Choice**

Core premises

- a. Individual choice and the right to remain in one's own community
- b. Establish across the board "medically needy" eligibility (annual eligibility)- instead of spenddown (which is temporary and month-by-month) for children and adults who have documented extraordinary expenses due to their complex and/or multiple medical and disability-related needs. (Currently Illinois has nine waivers, six of the waivers serve children and only two waive family income.)
- c. Allow access to PUNS (Prioritization of Urgency of Need for Services) for adults with DD enrolled in the new ACA Medicaid (which means that they are not on SSI)- streamline disability determination process.
- d. All participants will have a choice about participation in care coordination, including requesting training to enhance their own care coordination skills.
- e. Using a single point of entry is the way to go, but need to insure that "gatekeepers" have adequate training and specialization for persons with special health needs and/or disabilities. (Avoid the recent scenario where an MCO assigned a person with severe physical disabilities to a care coordinator who is an addiction counselor.)

- f. Have the same “ground rules” for all waiver-funded services and supports. (For example, eliminate the caveat that mandates PA care to be provided only within the walls of a person’s home, but literally not outdoors or in any community setting. For children, for example, allow 1:1 support staff to support children in integrated community settings such as day care and day camp.)
- g. Support and fully fund an array of home and community based direct care options, including (but not limited to) RNs, LPNs, CNAs, personal assistants, direct support professionals and personal support workers.

## **2. Delivery System Transformation**

- a. Increase reimbursement rates for both primary care and specialty care.
- b. Provide financial incentives for “blended” medical provider settings (where all types of private and public insurance are accepted)- vs. “Medicaid only” settings.
- c. Establish billing and reimbursement for medical care coordination services for both children and adults with complex needs.
- d. Establish framework for physician participation in the development of IEPs and 504 plans for school age children.
- e. Eliminate archaic bidding requirements and reimbursement protocols that can be barriers to persons seeking (for example) assistive technology, home modifications and durable medical equipment.
- f. Streamline enrollment and reimbursement for individuals as “private transportation providers”, and include coverage of parking fees for medical appointments.

## **3. Build Capacity of the Health Care System for Population Health Management**

Establish “inclusion in health care” as a core value - ensure full access, regardless of an individual’s specific needs, and mandate/monitor compliance with Section 504 and the ADA in all settings statewide.

- a. Provide full dental coverage for all enrollees, regardless of age.
- b. Ensure that mental/behavioral health services, including outpatient psychiatric care, are available to all enrollees statewide, regardless of age and/or type of special needs.
- c. Monitor and collect data on how individuals with special health care needs and/or disabilities are included in all health care settings (in-patient and outpatient), modifications/adaptations required and their cost.
- d. Permit telemedicine follow-up for behavioral health services only following in-person encounters (not in lieu of face-to-face appointments).
- e. Ensure that children with special health care needs/disabilities who “age out” of pediatric medical services are successfully transitioned to adult providers in their communities who are trained and prepared to serve them.

- f. For the small number of children with low-incidence medical needs for which “adult providers” cannot be located, ensure that they will be able to continue to access care at pediatric tertiary care centers (and not be limited to those participating in the current Integrated Care Pilot).

#### **4. 21st Century Health Care Workforce**

- a. Require and fund in-service training on oral health for all direct service professionals employed by programs/agencies funded by the 1115 waiver.
- b. Require and fund in-service training on mental health, as well as behavioral challenges, for all direct service professionals employed by programs/agencies funded by the 1115 waiver.
- c. Re-open the University of Illinois at Chicago Children’s Habilitation Clinic, which was closed in October 2013, after 57 years of operation.

This clinic has been a key provider of medical diagnostic and follow up care for children (up to age 21) with developmental disabilities and complex medical needs. In addition, it served as a training site for generations of our state’s student health care professionals and prepared them to serve patients with disabilities in primary and acute care settings in their own communities.

#### **5. General Comments**

1)Protect rights of enrollees and establish consumer-friendly grievance and appeal procedures

- a. Provide parents/guardians of enrollees up to age 21 with annual written information (at 3-4<sup>th</sup> grade reading level) of their child’s EPSDT rights, regardless of the type of health plan they are enrolled in.
- b. Re-establish the Ombudsperson’s Office and incorporate the current Client Assistance Program into it.
- c. Ensure that the Ombudsperson’s Office include “disability specialists” in addition to generalists.
- d. Set up online option for filing appeals, in addition to current fax and mail options.

2)Require transparency related to appeals and grievances via ongoing data collection and reporting available to the public.

- a. Annual reports on number of appeals, involvement (if any) of legal/advocacy agencies and outcomes.
- b. Annual reports on appeals/grievances handled by contracting Managed Care and Coordinated Care entities internally vs. those appealed at the HFS level.
- c. Annual reports on barriers encountered and best practices established resulting from data collected on appeals.

Please let me know if you have any questions or would like additional information regarding our recommendations.

We look forward to continued collaboration with you on behalf of Illinois residents with special health care needs.